Service of Remembrance

For

Donors
Donor Families
Recipients.

Saturday 31st May 2014
At RMIT Storey Hall, Building 16
336 Swanston Street  Melbourne
Doors open at 1.15 for 2.00pm start

Sponsored by donateLife.

The Big Red Kidney Bus rolls into Traralgon for the Launch—in it’s Town of Origin on 22 March 2014
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Editors Comment

Best wishes from all of us at DATA to you,
Michael. Hope you are feeling much like your old
self and home again real soon. !

The Remembrance Service, an annual event
will be held in Melbourne on 31 May 2014 -put that
date in your diary now! It is a very moving service and
one well worth attending especially if you and your
family have been touched by transplant. The Service is
being organised by DonateLife.

Hey Hey We are having a Xmas in July, a winter
celebration, probably different to our previous Xmas in
July. (As we have all passed our use by dates)

We plan to go to a ‘venue’ yet to be confirmed, and
have Xmas fare prepared for us. Cost will be in the
vicinity of twenty dollars per person So keep the date
free that is 26th July 2014

RON JONES EDUCATIONAL AWARDS.

Please note these are due in by 31st May 2014 See
page 8 & 9 for details.

Our Social gathering to Mornington Rose Garden was a
very pleasant outing well worth the effort. We enjoyed a
talk about the development of the Rose garden, then a stroll
(brisk walk) around the gardens which were all beautifully
kept thanks to all the Volunteers who help maintain the
grounds. We did forget the camera, so no photos, but there
were quite a few roses flowering.
Joan Eastwood

Presidents Report.

Greetings

This month I write to you from the Renal ward of Royal
Melbourne Hospital where I have been for four weeks – trying to save my
(transplanted) kidney. So you will understand that I am a little out of touch
with DATA matters! However, there are good committee members who, thankfully,
have ‘filled in’ in my absence and I thank them for this.

Next issue I should be home, from where I hope to be able to report on a successful transplant for a DATA volunteer. In
the meantime, my best wishes go to anyone currently undergoing transplantation or other medical procedures.

Once again, look after yourselves. More next issue.
Kind regards
Michael
The Renal Society of Australia and New Zealand held their fifth bi-annual Home Dialysis Conference in Melbourne in early March. The conference ran for three days and for the first time those on dialysis were invited to attend. The name of the conference was My Kidneys, My Choice, My Home.

This conference was attended by nephrologists, renal nursing staff, patients, renal technicians and Allied Health personnel. Nearly 400 people, including a number from overseas, attended. With local, interstate and international presenters the conference proved a huge success.

In the foyer there were stands with displays from a number of support organisations and suppliers of dialysis equipment. As well as the familiar Gambro and Fresenius equipment there were dialysis machines from Nxstage (USA) and Nipro (Japan) on display. Kidney Health Australia and the Home Dialysis Network also had stands. Unfortunately DATA was unable to organise a stand, however we were able to display a poster with thanks to Alastair from Dinamics (conference organiser).

The conference included an extensive programme of presentations conducted across three conference halls. In addition there was a display of Posters (sponsored by the Department of Health) on an array of topics relating to home dialysis.

At the start of each day’s programme there was a main presentation to everyone in attendance. This was followed by a series of breakout presentations in three separate areas and each person could choose which session to attend. With three concurrent sessions it was difficult at times to choose which to attend. Some sessions were aimed at medical staff, others were aimed at patients and carers and some were aimed at both groups.

Sessions of interest for patients included:

“Increasing and Improving Technologies” given by Richard Fluck from the English NHS,

“Short Daily Versus Long Hour Dialysis”, presented by Peter Kerr from Monash.

“Assisted PD the Austin Experience” (also presented on a poster), given by a nurse from the RDNS.


“Green Therapies” presented by John Agar, from Barwin Health. (Geelong).

“Artificial Wearable Kidney” presented by Andrew Davenport from London. This included a photo of a mother and daughter. The mother was on a conventional dialysis machine and standing beside her, was her daughter wearing a dialysis machine. This new technology received approval for human trials in the USA. And a short trial showed great possibilities with the hope it will be further improved and launched in about 5 years.

“Campervan Dialysis” presented by Tracy Thompson, a dialysis patient who now lives and travels in a campervan.

At lunch time on the final day attendees of the conference were given a preview of the Big Red Kidney Bus.
**ShoeString**

**Holiday Homes**

**Rosebud House Secretary: AMANDA PRATT phone: 9589 4894**

Next Vacancies:
- June 1st to June 8th
- July 20th to July 27th
- June 8th to June 15th
- July 27th to August 3rd
- June 22nd to June 29th

The Rosebud house has been busy over the summer months. We had a few cancellations which we were unable to fill, so please let me know if you would like to go on the last minute list.

We have FOUND a grey drop pearl earring in the house, if someone has lost it please let me know.

We have installed hand rails at the back door and laundry door. We have also purchased a new kettle.

Now is a great time to get away for a winter break. The house is fully heated and very cozy this time of year. Rosebud itself is not so busy as the summer months so easy to get around the shops. There are some lovely drives up to Arthur’s seat or Sorrento.

Remember you must be a member of DATA before you can use the houses but it only cost $10 a year to join.

If you need dialysis at the hospital, please ring them first before booking the house.

The Rosebud renal unit number is 59860776. I have also been contacted by the Hastings renal Unit to say they often have places available and they are only half an hour drive from Rosebud.

Hastings renal unit number is 59790344.

From Amanda Pratt

**Yarrawonga House Secretary ALAN RAWSON phone 9723 3019**

Next Vacancies:
- August 3rd to 10th, 10th to 17th, 17th to 24th.
- October 19th to 2nd Nov 23rd to 30th, December 23rd to 30th.

We do get cancellations so please ring me. We have ordered 2 new remote controls front garage doors for the house at Yarrawonga. The remote wall unit controls will be in the garage on the wall 1 for each door, we think the best way for now is to keep the present arrangement of having to still go in to the house to open the garage doors. We do not want members taking the remote controls home as it would then be hard for the next person.

When we were at the house in March we noticed that 4 of the bedside lamps have been damaged and the lid of the electric jug was broken. If you notice anything has been broken please notify me, we know that accidents happen. Remember the house is there for all members to enjoy a holiday, think of others please. If you have booked a fair way ahead, you must ring or E/mail me to confirm your booking within 3 months of going on your holiday.

Do not forget, if you need dialyse at Yarrawonga Renal Unit, please ring the hospital first to see what is available, then ring me to book the house, you must then ring the hospital to confirm the dates and book in straight away.

Do not leave it until you are about to go to Yarrawonga.

Alan Rawson

Remember you are responsible for the cleaning of the house which does include bathroom and toilet.

22 Tarwin Drive Croydon 3136, Ph. 9723 3019, e-mail: fayal_rawson@hotmail.com
**Blackburn House/Headquarters**

As you should all know our headquarters and city accommodation has been sold. We are able to extend the lease for another twelve months to February 2015. **The house is still available for anyone who wishes to stay** for a holiday visit, or who requires accommodation while receiving healthcare.

The cost of staying at the Blackburn house is $50 per room per night per membership and $20 a night for each extra person. If on a visit for medical reasons, accommodation payments may be paid by V.P.T.A.S. (Victorian Patient Assistance Scheme), ask your social worker for the details.

The house is self-catering so bring your own food, including tea, coffee, and sugar. You will also need to bring your own linen: sheets to fit a queen sized bed/single bed, pillowslips, towels, and tea-towels. (you are also responsible for cleaning after yourself, otherwise, an extra charge will apply)

Blackburn House is an easy walk to the train station and many bus routes stop at the station. Melbourne is a great holiday place so why not come for a holiday and explore this great city and stay at Blackburn. It is not here just for you to go for check-ups or hospital visits; it is here for holidays as well. We still have no plans where we will move to, nor when. When DATA knows what is happening we shall inform all our members.

Come and enjoy a stay at Blackburn and explore Melbourne.

Phone for bookings: **Contact: Ros. Ball 03 9439 8866**  
**Or Alan Rawson 03 9795 1649**

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**REMINDER:** YOU ARE NOT ALLOWED TO SMOKE IN ANY OF THE HOUSES.

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**Only in Dublin City Council:**

These are genuine clips from Dublin City Council complaint letters - so read and enjoy how others put their thoughts into words.

- My bush is really overgrown round the front and my back passage has fungus growing in it. \`
- He’s got this huge tool that vibrates the whole house and I just can’t take it any more.
- It’s the dogs mess that I find hard to swallow.
- I wish to complain that my father hurt his ankle very badly when he put his foot in the hole in his back passage
- And their 18 year old son is continually banging his balls against my fence. I wish to report that tiles are missing from the outside toilet roof. I think it was bad wind the other night that blew them off
- My lavatory seat is cracked, where do I stand?
- I am writing on behalf of my sink, which is coming away from the wall.
- Will you please send someone to mend the garden path? My wife tripped and fell on it, yesterday, and now she is pregnant.
- 50% of the walls are damp, 50% have crumbling plaster and 50% are plain filthy.
- The toilet is blocked and we cannot bath the children until it is cleared.
- This is to let you know that our lavatory seat is broke and we can’t get BBC2.

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Which side of the polar bear has the most fur  

*The outside of course!*
RICK and Sue Jakob call the machine ‘God’ – and it has given Richard his life back. After suffering complications from an operation on an abscess on his spine – the abscess exploded and turned septic, damaging his kidneys as it worked through his system – Mr Jakob has spent the last four years battling to keep his kidneys functioning, but when things took a turn for the worse in July this year, there was only one option left: dialysis.

While the couple had hoped for portable dialysis, they were soon told it would not be sufficient given the condition of Mr Jakob’s kidneys. The couple signed up to home nocturnal haemodialysis training and had the machine installed in their bedroom. After a successful trial run on Friday, Mr Jakob was able to start treating his condition in the comfort of his own home. Going on dialysis five nights a week for eight-hour stints, Mr Jakob said home dialysis freed up his days, allowing him to work full-time, and have left him feeling rejuvenated. “It’s definitely a life-changing machine,” Mr Jakob said. “You don’t realise how bad you felt until you feel this good. “You don’t realise how sick you were; I used to struggle along.” While he still got things done at his own pace, in July this year – just a month after he had a fistula placed in his arm in preparation for dialysis down the track – Mr Jakob noticed a change. “When I started going downhill, I knew there was something wrong,” he said. “I could sleep all day in the chair and wasn’t eating.” After a few days of extreme lethargy, nausea and itching, Mr Jakob went to a doctor requesting a blood test, before seeing his kidney specialist. She delivered a stark prognosis for the Camperdown man. “She said, ‘You’re going to have a cannula fitted in because you’re going on dialysis ASAP, otherwise in four days you’ll be dead’, ” Mr Jakob said. “My kidneys were deteriorating that badly and all the poison from my kidneys was going into my blood.” In a matter of days, the cannula was inserted and Mr Jakob had his first two-hour session of dialysis. “I got off after two hours and all I wanted to do was eat – I was back to normal,” he said. After some more treatment in Melbourne, Mr Jakob arranged to go on dialysis in Colac, before decided to undertake home dialysis. Clinical nurse specialising in home dialysis Tony Perkins, from Barwon Health, said one of the key advantages of home haemodialysis was it allowed patients nearly four times as much treatment as they would receive if they had the standard three four-hour sessions in hospital on a weekly basis. “This has added medical benefits: he’s going to feel a lot better because it’ll reduce the toxin that’s in his blood, but also because it’s at night-time, he gets his life back during the day,” he said. “He (Mr Jakob) can hold down a full-time job, he can go fishing if he wants to – he can honestly do whatever he likes. “That’s the benefit of this type of dialysis: you give much more autonomy back to the patient and they can take more control over the disease.” Since Professor John Agar, of Barwon Health, introduced nocturnal haemodialysis in Australia following a trip to Canada to learn about the treatment in the early 2000s, about 90 patients have been trained in home dialysis through Barwon Health. Mr Perkins said he believed Mr Jakob was the first in Camperdown to be part of the program, while there are currently five others west of Geelong undertaking nocturnal haemodialysis at home. Mr Jakob thanked local tradesmen Deiter McDonald and Gerard Ryan who installed the machine and fittings in his bedroom, in consultation with a technician from Geelong. He said he was also grateful to Rosemary Simmonds and the staff in Barwon Health’s renal unit who had helped him throughout the eight weeks of training in Geelong. Mr Jakob said he was feeling “100 per cent” better since he had been put on dialysis, and was looking forward to furthering a career with the SES – where he is a peer support officer – with his rediscovered vitality. “(I’ll probably) go back to studying and further my career in the SES with peer support and do more courses with peer support,” he said. “SES is basically the saviour of my life.”
Itchy Skin

Being told not to scratch is no advice on how to cope with itching!

- It is generally believed that high phosphate levels causes itchy skin, but there could be other causes as well. (see previous Shoestring issue on Phosphate)
- Skin can become very dry and itchy
- Uraemic toxins can build up and irritate the nerve endings in the skin
- Uncontrolled balance of calcium and phosphate, results in crystals being deposited into the skin.
- Magnesium can also build up and deposit crystals into the skin.
- Allergies to medication, lotions and such can make you itchy
- Heat will aggravate the skin.

Take your prescribed phosphate binders with meals, as directed by your doctor.
Try and stay out of the hot weather, and away from heaters
Use a moisturising cream on dry, irritated skin.
Use a soap containing a moisturiser, or try showering without using soap.
Use soap made for sensitive skin.
Wear “breathable clothing” and use cotton bed sheets to avoid sweet accumulation
Avoid using washing detergents with enzymes.
Try taking Evening Primrose Oil (with your doctors permission) or rubbed directly onto your skin.

Oatmeal

Tie up a handful of oatmeal into a muslin or cotton cloth. Boil the oatmeal as if cooking it for normal use.
Then use this cloth bundle as a sponge in a luke warm bath, or shower. Consider purchasing oatmeal bath products.

Itchy Cream Recipe sent to us by Ballarat Dialysis Unit.
originally printed in July 1994. Printed several times over the years and by popular request printed again.

Give this recipe to your pharmacist
0.5% phenol, 0.5% Menthol Olive Oil 0.5%
Make up in a Sorbolene base and use as required

From the Shoestring Archive March 1992

There are two days in every week about which we should not worry – two days which should be kept free from fear and apprehension.

One of these days is “yesterday”, with its mistakes and cares, its aches and pains, its faults and blunders. Yesterday has passed forever beyond our control. We cannot undo a single act we performed; we cannot erase a single word we said. Yesterday is gone.

The other day we shouldn’t worry about is “tomorrow”, with its possible adversities, its burdens, its large promise and poor performance. Tomorrow is also beyond our immediate control. Tomorrow’s sun will rise either in splendour, or behind a mask of clouds – but it will rise. Until it does, we have no stake in tomorrow, for it is as yet unborn.

It is not the experience of today that drives men mad – it is remorse or bitterness for something which happened yesterday and the dread of what tomorrow may bring.

Let us, therefore journey on –ONE DAY AT A TIME.
1. These Awards are to be known as the *Ron Jones Educational Awards*. They are to honour the memory of a founder and long time dedicated worker for DATA, Mr Ronald N Jones AOM.

2. The purpose of these Awards is to encourage scholastic achievement.

3. The Awards will be judged on scholastic ability exclusively assessed by a panel of judges accepted by DATA. No correspondence will be entered into.

4. An applicant must be either a financial member of DATA with chronic renal disease or the child of a financial member of DATA who has or did have chronic renal disease.

5. An applicant must have completed any of years 7 to 11 and may apply for an Award by the end of May of the following year for presentation at the AGM of that year.

6. Assessment will be judged on an Applicant’s previous year’s full school reports together with a 300-word handwritten essay on the topic of ‘My Chosen Career’. Failure of an Applicant to submit full years’ reports may, in the discretion of the DATA Committee or the Judges, result in the disqualification of that Applicant.

7. The amount to be expended each year will be $2000.00 and any amount not expended in any one year will not be available for use in subsequent years. Provided there are sufficient Applicants with merit, there will be:
   a) One (1) Award of $800.00 based on demonstrated excellence and scholastic ability.
   b) Three (3) Awards of $400.00 each for encouragement of future academic achievement.

   If, in any one year, no Applicant demonstrates a sufficient degree of excellence, the judges may, in their discretion, withhold the Award of $800.00 based on excellence and scholastic ability. However, irrespective of the standard of the Application and provided that there are sufficiently qualified candidates, the judges must award three (3) encouragement Awards.

8. Notice of the Awards will be advertised in at least three subsequent editions of ShoeString starting in the November edition of each year.

9. Applications will be printed in ShoeString and should be forwarded to the DATA Office by the end of May. Late applications will not be accepted.

10. **Schedule of Deadlines for Applications and Judging.**

    | Event                        | Deadline          |
    |------------------------------|-------------------|
    | Close of Applications        | end of May        |
    | Applications to Judges       | last week of June |
    | Results from Judges          | second week in September |
    | Advising Award Winners       | 3 weeks before the AGM |
    | Presentation of Awards       | at the AGM in October |

11. An Award winner cannot apply for another Award for another two (2) years. An unsuccessful Applicant can apply in subsequent years.

12. Awards will be presented to the successful Applicants at the AGM of each year. Parents will be invited to bring the Award winner to the AGM to receive a Certificate of Achievement or a Certificate of Encouragement.

13. The awards will be presented by Mrs. Elvie Jones, a Ron Jones family member (i.e. Mark or Dirk) or the President of DATA.

14. Privacy: No personal information given in an Application will be available to anyone. The only exception to this rule will be that an Applicant’s age, school reports (with the Applicant’s name and School obliterated) and the essay will be available to Members of the Judging Panel. Further, this exception will apply to a Sub-Committee specifically nominated each year by the DATA Committee to process the Award Applications. Those nominated persons will work in accordance with all Privacy Laws applicable in Victoria.

   Applications forwarded to the Judges will have a code of identification known only to the nominated Sub-Committee.

15. **Amendment:** These Rules may be amended by a majority decision at any validly constituted DATA Committee meeting provided that the Members of the Committee have been given at least 7 days notice of the proposed changes.

Rules amended 7 October 2008
Application for Ron Jones Educational Award

APPLICATION FORM FOR THE RON JONES EDUCATIONAL AWARDS.

Applications are requested to complete this form and forward it to
The Secretary
D.A.T.A. Vic Inc.
P.O. Box 165, Blackburn 3130.

Applications must be received no later than the 31st May 2013. Winners will receive awards at the A.G.M in October.

Applications must include a handwritten essay of 300 words entitled “MY CHOSEN CAREER.”

Also include the previous year’s school reports.

Please fill in this form using Block Letters.

SURNAME…………………………………………. GIVEN NAMES………………………………………………

ADDRESS……………………………………………………………………………………………………………………

POST CODE…………………………………… DATE OF BIRTH……………………………………

HOME PHONE…………………………….. MOBILE……………………………………

PARENTS / MEMBERS PARTICULARS
(IF APPLICANT MEMBER IS UNDER 18 OR A CHILD OF A MEMBER)

SURNAME…………………………………………. GIVEN NAMES………………………………………………

ADDRESS……………………………………………………………………………………………………………………

POST CODE…………………………………… PHONE………………………………………… MOBILE……………………………………

SIGNATURE OF STUDENT…………………………………………………………………………………………

SIGNATURE OF PARENT………………………………………………………………………………………………

Financial Member of D.A.T.A

YES NO

MY ESSAY ON “MY CHOSEN CAREER” AND SCHOOL REPORTS FOR THE LAST YEAR ARE ENCLOSED.

YES NO

SCHOOL PARTICULARS:

PRESENT YEAR OF STUDIES……………………………………

SUBJECTS STUDIED

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Media Release

World First Big Red Kidney Bus Celebrated in Traralgon

The Traralgon Lions Club hosted the Big Red Kidney Bus community launch; celebrating the world first mobile dialysis unit, at the Traralgon Farmer’s Market on Saturday, 22nd March. A vibrant display of the Latrobe Valley Community’s dedication to kidney health and making the world a better place, an estimated 1,500 people of all backgrounds celebrated the community launch with tours of the bus, heartfelt speeches, live entertainment, face painting and health education. Thousands of Australians on dialysis can now experience the joy of travel without missing life-sustaining treatment.

In January 2011, Vince Tripodi shared an idea with his family and fellow dialysis patients. Vince, like all dialysis patients, was restricted to a regimented routine of dialysis treatment, limiting his chances to travel due to decreasing dialysis places statewide. Vince thought,

“What if there was a bus that could go anywhere? A mobile dialysis unit; fully equipped with dialysis machines and knowledgeable and nurturing health practitioners; that could travel to various popular tourist destinations and be accessible for people who require dialysis treatment.”

A small group of highly dedicated Latrobe Valley dialysis patients and carers formed the Mobile Kidney Dialysis (MKD) group. The group, supported by Kidney Health Australia; Kindred Spirits Foundation; and many others, continue their journey for patient freedom despite Vince, Suzi Picken, and Bruce Bremner having since passed away; this bus their legacy to remind everyone that if we put our mind to it, anything is possible!

The community launch was everything the MKD group hoped for and more. Latrobe Valley Bus Lines’ Rhonda Renwick was overwhelmed by the community support, and ecstatic to see people learning about health and wellness. The volunteers met every task and every guest with vigour and enthusiasm, passionately proclaiming that the Big Red Kidney Bus is ready to hit the road. Billy the Kidney engaged children with filtered water in reusable bottles, and entertainer John Bagshaw pleased the crowd with his acoustic guitar from morning to afternoon. Experts from Kidney Health Australia supported the kidney health message, for those with renal failure, and for those with healthy kidneys, the lifestyle choices to keep them that way.

Tears of elation were shed by many. For some this is the first time they have encountered the idea, and the prospect of freedom for themselves or a loved one was simply overwhelming. For the MKD group this is the realisation of three years of hard work, and a shining beacon of remembrance for their loved ones past. The pain of loss is fresh in the hearts of the MKD group and the dear family and friends of Vince, Suzi, and Bruce. These humble heroes never got to experience the freedom the Big Red Kidney Bus is set to bring, but they passed knowing their efforts would better the lives of dialysis patients for years to come.

-Ends-

Media Enquiries
Eloisa Tripodi
Mobile Kidney Dialysis Group
0448 396 186
eloisatripodi@gmail.com

Editors note: There are many and varied holiday opportunities for Dialysis patients, each one suiting different needs. The Big Red Kidney Bus is yet another opportunity for Renal people to enjoy a holiday whilst relying on the machine for dialysis.
We had a good time at Blackburn at the Members BBQ. There were 14 of us present and we did not get too wet—we met some interesting people - Pat and Trish and Alan, Denise and her family and we shared our stories.

Have a look at the pictures—we started outside and finished in the garage at Blackburn.

The Launch of the Big Red Kidney bus in Melbourne on the steps of Parliament House March 13th.

Top left  Amanda Pratt, (speaking) Jo and Anne from Kidney Health Australia and two volunteers.

Top right: Let the fun begin Cheers
Second Launch of BRKB in Traralgon
Jo Fairburn in forefront of picture KHA.
**Dates to Remember**

- **31 MAY 2014**
  Applications due in for RON JONES EDUCATIONAL AWARDS

- **25th-31st May**
  Kidney Health Awareness Week

- **31st May 2014**
  Memorial Service Donatelifed Saturday 31 May 2014
  Doors open at 1.15pm for 2pm start.
  At RMIT Storey Hall, Building 16
  336 Swanston Street  Melbourne

- **Christmas in July  27th July  Venue TBA**

- **26th September-5th October Australian Transplant Games To be held in Melbourne**

Watch our Web site www.datavic.org

Find us on Facebook.

**Our thanks to all who contributed to this edition.**

Why not spread the word and pass this copy on?

*ShoeString* are always looking for stories to publish. If you have a story to tell and you’re not sure where to begin our editors would be more than happy to assist you in writing your article. Or if you have ideas of issues you would like to see covered, contact us.

*Write to:* The Editor, ShoeString,
PO Box 165 Blackburn 3130
*Email:* editor.shoestring@gmail.com

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**Deadline for the next ShoeString: 12June 2014**